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The Self-Reported Needs and Reflections of Caregivers of Brain Injury Survivors

by

Katelyn M. Ryan, B.A.

MSW Clinical Research Paper

Presented to the Faculty of the
School of Social Work
St. Catherine University and the University of St. Thomas
St. Paul, Minnesota
in Partial fulfillment of the Requirements for the Degree of

Master of Social Work

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Colin Hollidge, Ph.D., LICSW (Chair)
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The Clinical Research Project is a graduation requirement for MSW students at St. Catherine University/University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with basic social research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by a research committee and the university Institutional Review Board, implement the project, and publicly present the findings of the study. This project is neither a Master's thesis or nor a dissertation.

Abstract

This study seeks to examine the experience of family members of brain injury survivors in regard to the accessibility, helpfulness, and the effects of the information, resources, and support that they received from professionals during the recovery period, post injury. This research was qualitative and was completed through the use of a semi-structured interview schedule. Participants were asked questions which facilitated the exploration of six different topic areas in order to gain an understanding of the participants' and their families' experience throughout the recovery process following the occurrence of a brain injury of a family member. The six areas that were explored were: knowledge and awareness of brain injury, family/caregiver, long term effects of brain injury; the family's way of coping and adaptation, advice for others who have a family member that has recently suffered a brain injury, as well as additional necessary resources, supports and educational needs. The research found that nine themes emerged. These themes include: lack of general brain injury awareness, misdiagnosis, stress and change in family roles; lack of family effects information and resources provided; prevalence emotional and mental health effects; lack of information provided on long term effects; family support and developed strengths. Results indicate a need to increase the amount of and availability of brain injury educational information, resources and support for brain injury survivors and their families.

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Introduction

When thinking of studying brain injuries, a likely choice of study is to look at the effects of the brain injury on the survivor, or even the ripple effects that the brain injury has on the family members and caretakers of the survivor. Survivors are asked about their life post-injury and the effects that their brain injury has had. Family members and caretakers are asked to describe the changes that they have seen in the survivor and how the family system has been affected. Advances in brain injury research as well as emergency medical technology and diagnostic tools continue to be made, increasing the number of those who survive head injuries that would have had little chance of survival in the past.

Each year in the United States, an estimated 1.5 to 2 million people sustains a traumatic brain injury. Among these 1.5 to 2 million people, 70,000 to 90,000 people will experience long-term functional impairments as a result of the injury. Around 50,000 individuals will not survive the first year. There are at least 5.3 million Americans that are currently living with a brain injury (Degeneffe, 2001). Brain injury is the leading cause of death and disability among Americans between the ages of 1 year old to 44 years old (Maas et al., 2008). More than 80,000 American youth are hospitalized due to a brain injury each year and more than 11,000 of those American youth die (World Health Organization, 2014). In the United States alone there are so many people permanently disabled from brain injuries that each decade those individuals could fill a city the size of Detroit. If this were to be done, there would be seven of these cities filled already, one-third of them filled with survivors less than fourteen years of age (Mason, 2008).

An individual who has sustained a brain injury can encounter a large number of physical, cognitive and emotional effects. These effects can appear immediately following the injury or in the days, weeks, months and even years following. Many studies have been done to document the wide range of effects and changes that a brain injury survivor may encounter both short-term and long-term, following an injury. A brain injury is never an isolated incident. Brain injuries can “collapse a family and flatten a business, evaporate friendships and allegiances, overburden a community, and buckle a state’s health care system” (2008). The brain injury survivor may lose the functional ability needed to return to living independently, socially interacting, working competitively and meet the other important personal and family needs that were able to be met prior to the injury.

Within the last decade much scientific research has been completed on the effects of brain injury on the individual as well as the social and family system effects. This surge in brain injury research is largely due to the number of veterans returning from combat in Iraq and Afghanistan with brain injuries as well as the rise in reports of sports related concussions. The devastation of brain injury can be seen through the numbers of incidence and the research completed about the large range of effects. As the leading cause of death and disability in the United States for individuals under the age of 45, brain injuries occur more frequently than AIDS, breast cancer, multiple sclerosis, and spinal cord injury combined. Despite the pervasiveness of brain injuries and the recent increase in research completed, brain injury remains the “silent epidemic” due to the lack of public knowledge regarding the research that has been done surrounding the topic as well as the high number of undiagnosed and misdiagnosed acquired and traumatic brain

injuries. According to a recent national survey, only one in three Americans are familiar with the term “brain injury” (University of Pennsylvania Center for Brain Injury and Repair). Also, each year countless brain injuries go undiagnosed as a result of under awareness, underreporting, under diagnosis and misdiagnosis. The large number of undiagnosed traumatic brain injuries creates a worrisome problem due to the proven links between head injury and mental illness, criminality and substance abuse (Buck, 2011).

It is apparent that up to date, American citizens are vastly unfamiliar with the definition, prevalence and effects of brain injuries regardless of the continuing flux in research. Therefore, it can be assumed that most brain injury survivors as well as their family members enter in to the chaotic world of brain injury with a lack of even the most minimal knowledge surrounding the subject, let alone the long-term effects. It is therefore important that health care, mental health and appropriate social service professionals provide brain injury education, resources and support to brain injury survivors and their family members or caretakers. It is also important that this information be provided at an appropriate time within the recovery period, post-injury.

This research is a qualitative, exploratory study, asking family members and caretakers of brain injury survivors to provide their personal experiences surrounding accessibility, helpfulness, and the effects of the information, resources, and support that they received from professionals during the recovery period, post injury. The purpose of this study is to gather information on what brain injury educational information, resources, and support are necessary for professionals to provide for family members and caregivers of a brain injury survivor throughout the initial recovery process, as well as to

gather information on the appropriate stages to offer educational information, resources and support.

Literature Review

There are at least 5.3 million Americans living with a permanent disability resulting from a brain injury (Mason, 2008). Due to advances in emergency health care technology many who would have died in the past as a result of their head injuries, now survive. A brain injury affects nearly everyone and everything associated with the survivor. Brain injuries create a large range of effects that immerge immediately following the injury as well as in the days, weeks and even years following that require adequate education, support and resources in order for all involved to cope and adapt. The following literature review will examine the different types of brain injuries as well as the recovery period following a brain injury. Lastly, this literature review will examine the effects of a traumatic brain injury not only on the survivor but also on the family as a whole.

Types of Brain Injuries: Definitions, Differentiations & Severity

Whether you are reading about brain injuries, listening to an individual discuss them or attempting to speak on the topic yourself, the task of deciphering what specific type of brain injury is being referred to or what name to use when speaking on a specific type of brain injury yourself can be confusing. There are multiple types of brain injuries and within each type of brain injury there are different classifications of the injury. Therefore, it is not uncommon to hear an individual loop all brain injuries into one

category or the other or use the different types of brain injuries interchangeably. The Brain Injury Association of America states in The Essential Brain Injury Guide that in regards to brain injuries: “establishing a uniform working definition has been difficult and controversial. No universal definition can be all inclusive and uniform for surveillance and research, yet simple and understandable enough to facilitate public response to education and prevention efforts” (2009).

The Brain Injury Association of America finally adopted a definition of acquired brain injury or ABI in 1997. The definition was created in order to broaden the definition of brain injury beyond that of only being produced by trauma. The definition created for acquired brain injury is “an injury to the brain that has occurred after birth and is not hereditary, congenital or degenerative. The injury commonly results in a change in neuronal activity, which affects the physical integrity, the metabolic activity or the functional ability of the cell” (2009). The definition of an acquired brain injury is comprehensive and includes not only injuries to the brain that have been caused by external physical force, but also includes internal insults to the brain.

There are many known causes of acquired brain injury. An acquired brain injury may occur following external insult to the brain, resulting in traumatic brain injury. It also can occur following many different types of internal insults such as strokes, cardiac arrest, tumors, blood clots, and seizures; infections such as encephalitis and meningitis, and metabolic disorders such as insulin shock, diabetic coma, and liver and kidney disease (Iskander, Cohen & Kapoor, 2010). The three leading causes of acquired brain injury annually are stroke (795,000 incidents), tumors (64,530 incidents), and aneurysms (27,000 incidents), followed by viral encephalitis, multiple sclerosis, and anoxia/hypoxia.

Anoxia occurs when there is a reduction in oxygen supply to the brain whereas hypoxia occurs when there is a complete lack of oxygen to the brain. Anoxia and hypoxia can be caused by some of the previously mentioned sources of acquired brain injuries such as strokes and cardiac arrest. Both conditions can also be caused by many other incidents such as near drowning, drug overdose, strangulation, carbon monoxide inhalation and poisoning. Both anoxic and hypoxic brain injuries can occur despite sufficient blood supply to the brain (Middelkamp et al., 2007).

The National Head Injury Foundation, now known as the Brain Injury Association of America adopted a definition of a traumatic brain injury in 1986. The definition adopted for a traumatic brain injury is:

an insult to the brain, not of degenerative or congenital nature but caused by a external physical force, that may produce a diminished or altered state of consciousness, which results in an impairment of cognitive abilities and/or physical functioning. It can also result in the disturbance of behavioral or emotional functioning. These impairments may be either temporary or permanent and cause partial or total functional disability or psychosocial maladjustment (2009, pg. 2).

This definition of traumatic brain injury is still used today as the standard definition of use by all advocates in the development of services as well as in data registries. There are many different causes of traumatic brain injury. Some of these causes include: motor vehicle accidents, falls, gunshot wounds, sports injuries, workplace injuries, shaken baby syndrome, child abuse, domestic violence, military actions, and other injuries caused by an external force. The break down of typical causes of traumatic brain injury is as follows: falls result in 22% of TBIs, motor vehicle accidents cause 17% of TBIs, being struck by or against an object or surface leads to 16% of TBIs, and assaults result in 10%

of TBIs. The remaining 22% of causes of TBIs are in the “other” category. (Brain Injury Association of America, 2009).

An important distinction to make when classifying traumatic brain injuries is the difference between open head injuries or penetrating head injuries (PHI) and closed head injuries (CHI). Open head injuries occur when the skull is penetrated, leaving the brain exposed. Closed head injuries occur when there has been no penetration, leaving the skull intact but the brain still impacted by the trauma. According to Ghajar (2000), not all of the neurological damage occurs immediately at the moment of impact (primary injury) but can evolve afterwards (secondary injury). In fact, “secondary brain injuries are the leading cause of in-hospital deaths after a traumatic brain injury”. Brain swelling creates a lack of oxygen to the brain, furthering brain damage and morbidity, and is the most frequent cause of secondary injury (2000).

Aside from brain swelling, when classifying brain injuries there are multiple terms used for common and specific injuries to the brain that occur as either the primary or secondary injury. These terms are used to describe the structural damage to the brain. The most common of these injuries is a concussion. Concussions occur when the brain receives trauma from a sudden momentum or movement change, or from impact. Within the brain the blood vessels may stretch and cranial nerves may be damaged. Contrary to common belief, concussions can cause substantial difficulties and impairments that can last a lifetime (Marar, McIlvain, Fields, & Comstock, 2012). Other terms used to describe specific structural injury to the brain include: contusion, coup-contra-coup, penetrating, through-and-through, and diffuse axonal (Finnie & Blumbergs, 2002; Brumback, 1996; Williamson, Scott, & Adams, 1996).

When determining the severity of a brain injury, customarily an approach is used in which three different categories are assessed, two of them having been previously discussed: mechanism (closed head injuries versus open head injuries) and structural damage (concussion versus coup-contracoup injury). The third category that is used in the assessment to help determine the severity of a brain injury is clinical severity. In order to assess clinical severity the Glasgow coma scale is used to determine level of consciousness following an injury. The score of a GCS combines the values from three tests, eye, motor, and verbal:

Eyes: 1=no response; 2=open in response to pain; 3=open in response to speech; 4=spontaneous. Motor: 1=no response; 2=extension to painful stimuli; 3=abnormal flexion to painful stimuli; 4=flexion/withdrawal to painful stimuli; 5=localizes painful stimuli; 6=obeys commands. Verbal: 1=no response; 2=incomprehensible sounds; 3=inappropriate utterances; 4=disoriented, confused; 5=oriented, converses normally (Maas, Stocchetti, & Bullock, 2008).

Scores range between 3 and 15 and the lower the score, the more severe the brain injury is (Maas, Stocchetti, & Bullock, 2008).

Effects of Traumatic Brain Injury on Patient

Short-Term & Long-Term Effects. There are many short-term and long-term effects of brain injury. A person who has suffered a moderate or severe brain injury will likely experience a mix of physical, cognitive and affective impairments (Cloute, Mitchell & Yates, 2008). Some common short-term affects one may experience are nausea or vomiting, aphasia; a headache that does not go away, convulsions, an inability to awaken, restlessness, dilation of pupils, confusion, dysarthria, slurred speech, weakness or numbness in the limbs, loss of coordination, or agitation. Some of the common long-term symptoms of a moderate to severe brain injury are deficits in social

judgment, changes in appropriate social behavior, and cognitive changes, especially problems with processing speed; depression, sustained attention, and executive functioning (2008). Alexithymia, a deficiency in one's ability to understand, identify, describe, and process emotions occurs in 60.9% of the individuals who have sustained a traumatic brain injury. Cognitive and social deficits have long-term consequences for the daily lives of people with moderate to severe traumatic brain injury, but can be improved with appropriate rehabilitation (The Brain Trauma Foundation, 2009).

Another reason that brain injury is often referred to as the “silent epidemic” is due to the fact that many of the major post-brain injury disabilities are neuropsychological and are not immediately apparent following the injury but may develop months or years following the injury. Due to the fact that these injuries are not physically apparent, they are in a sense, hidden injuries. Problems with memory, emotion regulation, concentration, fatigue and sleep are common (Cloute, Mitchell & Yates, 2008).

Cognitive Impairment. Impairments such as reduced concentration, slowness, loss of normal abilities to plan, schedule, monitor and inhibit activity are commonly reported following a brain injury. Two of the most common impairments following a brain injury are problems with memory and difficulty with higher communication. In many patients damage to several areas of the brain leads to difficulty with creating and storing new memories as well as both implicit and explicit memories. Communication difficulties are also prevalent in individuals who have suffered a brain injury. Following a brain injury higher level communication skills such as understanding metaphor or sarcasm and complying with conversation rules such as turn taking are often lost (Allin & Fleminger, 2006). These impairments not only directly affect these specific processes but

also take a toll emotionally on the individual as they often lead to difficulties maintaining contact within their social networks.

Emotional & Mental Health Effects. According to Vaishnabi (2009) neuropsychiatric problems are more prevalent and longer lasting than in individuals from the general population. About 40% of those who have endured a traumatic brain injury suffer from two or more psychiatric disorders. Neuropsychiatric problems can occur anytime following a traumatic brain injury and can vary in severity ranging from “subtle changes in mood, behavior, and cognition to severe depression, significant agitation, or dementia” (2009). Anxiety disorders are common following any brain injury and have been found to occur in nearly 30% of all patients. Anxiety disorders and symptoms can develop as frequently in individuals who have suffered a mild brain injury as they can in individuals who have suffered a moderate or severe brain injury (Allin & Fleminger, 2006). Major depression has been found to occur in one-quarter of all patients following a traumatic brain injury (Fedoroff et al., 1992).

Loss of Self & Suicide. When considering the complexity of changes that one faces following a brain injury it is not surprising that there are high rates of depression and an increased likelihood of suicide among brain injury survivors. Perhaps one of the most frustrating aspects of brain injury for an individual to deal with is the adjustment to post-injury life, the long-term and sometimes life long impairments caused by the injury in general. These impairments leave individuals grieving a “loss of self”. Niemeier and Karol (2011) state that persons with a brain injury often report saying, “I just don’t feel like myself” and describe it as being a loss that is hard to put into words. Research has attributed this feeling of loss of self to the individual’s new physical, cognitive and

emotional deficits that change the way they are used to thinking, feeling, reacting, and communicating as well as often changing the roles they are used to playing within their family, social and professional circles, or society as a whole. This feeling of the loss of oneself can cause severe disruption in self-image and interpersonal relationships (Landau & Hissett, 2008).

Cabezas (2001) studied the prevalence of suicide in brain injury survivors. The researchers followed the recovery of 39 individuals who had suffered a traumatic brain injury until a year and a half following the injury. The researchers used the Rorschach approach to study the personality and emotional functioning of the 39 individuals. The study showed that 48.6% of the studied individuals could be categorized as clinically depressed and of these, 65% of them were at a clinical risk to commit suicide (2001). A study conducted by Simpson and Tate (2002) examined the prevalence of hopeless, suicide ideation and suicide attempts following a traumatic brain injury in a sample of 172 outpatients with a traumatic brain injury. Out of the 172 individuals in their study, 35% had clinically significant levels of hopelessness and 23% had suicidal ideation. Their study concurs with Cabezas' study and found that 18% of the outpatients recovering from traumatic brain injuries in their study had attempted suicide. It has also been found that those who have suffered a brain injury are four times more likely to die by suicide than the general population (2002). Interestingly enough, increased rates of suicide have been found even in those who have sustained a concussion (Wasserman et al., 2008).

Behavioral Effects. Personality changes as well as behavioral problems are common following a brain injury. Behavioral problems in those who have suffered a

brain injury can lead to psychiatric hospitalization. Common behavioral problems that have been seen in those recovering from a brain injury are agitation, aggression, social inappropriateness, a-motivation, and impulsivity (Vaishnabi, 2009). In a recent study, Churchwill (2011) set out to find neurological proof of correlation between a brain belonging to an individual who has suffered a traumatic brain injury and impulsive and suicidal behavior. In his study, Churchwill compared the brain scans of fifteen male veterans who suffered a traumatic brain injury and brain scans of seventeen healthy, controlled males. The researchers involved in this study identified the presence of white matter on the brain scans as an indicator for impulsivity and adaptability to suicidal behavior. The brain scans showed that those individuals who had suffered a traumatic brain injury had increased amounts of white matter, demonstrating a neurological predisposition for impulsivity and adaptability to suicidal behavior (2011).

Recovery Period Post Traumatic Brain Injury

Previous research has shown that the time frame for physical, cognitive and emotional recovery following a brain injury differs from one another. Fleminger (2010) states that there is a correlation between the stage an individual is at in their brain injury recovery and their mental health status. The period of time post brain injury that has been identified as the stage in which an individual is most likely to become depressed is between one and two years following the injury. This period of time is called the critical period due to the fact that most physical and cognitive improvement has begun to slow down. The brain injury survivor will begin to feel a plateau in recovery during the critical period and notice which effects may be long-term, life changes (2010). However, while

most physical and cognitive improvements are made within the first two years following the injury, in some patients further improvement is seen as late as five to ten years after the injury (Ponsford & Fleminger, 2005).

There are multiple studies that have been done to examine the recovery period following a traumatic brain injury. According to Van Zomeren and Van Den Burg (1985), Oddy interviewed a group of 50 young adults who all experienced post-traumatic amnesia for over 24 hours following their brain injury, six months following their accidents. Less than a quarter of these individuals claimed to be symptom-free. The patients who reported that they were still experiencing effects of their brain injury reported the following complaints:

Trouble remembering things (38%), often losing temper (35%), becoming tired very easily (33%), having difficulty concentrating when reading (29%), often irritable (29%), often impatient (27%), often restless (27%), and finding difficulty becoming interested in anything (21%) (1985).

Another study on the time from for recovery of brain injury survivors was conducted by McKinlay (1985) in which the psychological changes in patients were reviewed at three, six, and twelve months post-injury during interviews with patient's close relatives. During the twelve-month interviews, six problems were mentioned with high frequency. The problems that were mentioned are: irritability (71%), impatience (71%), tiredness (69%), poor memory (69%), slowness (67%) and bad temper (67%) (1985). To examine the symptoms of brain injury still present after a longer period post-injury, Van Zomeren and Van Den Berg (1985) distributed a questionnaire to fifty-seven brain injury survivors two years after sustaining a severe brain injury. The study found that 84% of the patients still reported some residual psychological deficits. The most common reported deficits

were forgetfulness, irritability, slowness, poor concentration, fatigue, and dizziness (1985).

While the recovery of an individual following a traumatic brain injury is complex and varies from person to person it has been found that in a mild traumatic brain injury, cognitive recovery tends to be rapid and will leave the individual returning to baseline functioning within three months following the injury (Vaishnabi, 2009). However, for an individual who suffered a moderate to severe traumatic brain injury, cognitive recovery in comparison to their baseline cannot fully be seen until two years post injury. Functional recovery is rapid within the first few months following the injury and then followed by gradual plateauing. Recovering from behavioral and neuropsychiatric symptoms after a moderate to severe traumatic brain injury is a more complex process that involves frequent remissions and relapses (2009). Cloute, Mitchell and Yates (2008) state that at twelve months following the occurrence of a brain injury, it is the behavioral and cognitive consequences that appear most prevalent and can have potentially devastating social implications for the survivor, leading to increased feelings of loss of self and social isolation.

Strandberg (2009) set out to identify how individuals who have suffered a traumatic brain injury deal with life events. Researchers involved in Strandberg's study performed in-depth interviews with fifteen people who had sustained traumatic brain injuries. The life events that the researchers were interested in discussing with the participants were returning to work, social integration, family life post-injury, every day life, and overall life satisfaction. The researchers referred to the participant's adjustment to these life events as the change over process. All fifteen expressed that it was a struggle

to return to social interaction following the injury and that it was also extremely difficult to adjust to decreased independence. The participants also reported struggling with emotional control. The challenges that the participants reported during their interviews also led them to report that they felt less satisfied with every day life than they had before the injury. Most importantly this study identified the participant's unanimous belief of support and care being the most essential piece to their recovery. The fifteen participants reported that the support that they received and the resources available for them and their family were plentiful immediately following the injury and dwindled as time progressed, leaving them to deal with the permanent effects of the injury on their own (2009). Saout (2011) offers the opinion that treating an individual who has suffered a traumatic brain injury requires multidisciplinary care and support on both medical and social levels.

Effects of Traumatic Brain Injury on the Caretaker & Family

While it is expected that the brain injury survivor will experience a wide range of effects following the injury, the ripple effect that the injury has on the family as a whole can often be overlooked. The devastation that is associated with a brain injury is often beyond comprehension until the complexity of the injury is understood. Brain injuries differ from other physical injuries in that a medical intervention cannot resolve all of the problems. Recovery is often long, filled with uncertainty and dependent upon access to rehabilitation services and support systems for both the individual and the family. The individual who sustained the brain injury may lose the functional ability needed to return to living independently, socially interacting, working competitively and meet the other important personal and family needs that were able to be met prior to the injury.

According to The Brain Injury Association of America (2009), there are certain factors that can be used to predict a family's ability to adjust to the changes created by a family member sustaining a brain injury such as pre-injury cohesiveness, family attitudes about illness and responsibilities, as well as available economic and social supports.

Studies have identified increased levels of stress and depression in family members of individuals who have sustained brain injuries, especially in the primary caregiver. Cognitive changes in a brain injury survivor such as visual perception, attention, concentration, problem solving, abstract reasoning, emotional regulation, information processing as well as noticeable changes in the family due to the accident have been identified as changes that cause large amounts of stress and a need for necessary adaptation by both brain injury survivor and their family (Degeneffe, 2001). Brain injury survivors as well as their family members have reported that the stress levels within the family do not decrease within the first five years following the injury due to the fact that resources and support outside of the family become less widely available the longer it has been since the injury (2001).

Stages of Family Adjustment. While some families may be predisposed to having an easier adjustment, every family goes through stages of adjustment. The Brain Injury Association of America (2009) identified six stages of adjustment for families. The first stage of adjustment takes place between one and three months post-injury. During this time the family experiences shock and hopes for a full recovery in a short period of time. The family also often develops denial of the severity of the situation during this time period as they continue to hold on to the belief that their family member will wake up and return to life prior to the injury. The second stage takes place between three to

nine months post injury. Within this period of time the family continues to adjust to the situation and begins to acknowledge the severity of the situation. Feelings of helplessness, anxiety, anger, fear, depression, loss and frustration often escalate during this time. The Brain Injury Association of America explains, “they realize that the person has a serious condition and they lack the knowledge about what will happen next or what they can do” (2009). Stage three occurs between six to twenty-four months following the injury. During this time family members may still expect that the survivor will again reach independence and may become annoyed with the survivor while also experiencing depression, guilt and discouragement as they slowly begin to recognize the reality of the impairments. Within this stage family members frequently begin to seek information about brain injury. Stage four occurs between ten to twenty-four months post injury. This stage is the beginning of realism for the family as they continue to witness the disabilities caused by the brain injury. During this period some family members may reduce the amount of time that they spend with the survivor as exhaustion and emotions similar to bereavement set in. The fifth stage takes place between twelve and twenty-four months following the brain injury. The grieving cycle often starts over again during this stage as the family experiences extreme sadness while dealing with the loss of the survivor’s personality traits and future plans. The final stage of adjustment for families takes place between two to three years after the injury. By the time a family has reached this point they have usually invested more time in understanding the severity of the injury as well as what the future may hold. Family members during this period accept that the survivor may never be the same person they were prior to the injury (2009).

Grief & Loss. Each family reaches the different stages of adjustment at their own pace, in accordance to their specific family situation and severity of the injury. However, in dealing with a brain injury every family deals with feelings of grief and loss. Grief is a normal and healthy reaction to loss. However, the feelings of grief and loss that can be experienced by family members of a brain injury survivor commonly differ from the feelings of grief and loss experienced by those who are dealing with the death of a loved one. Ambiguous loss is an externally caused, unclear, traumatic and incomprehensible loss (Bryan & Peck, 2009). There are two types of ambiguous loss. The first type of ambiguous loss is felt following a physical absence with psychological presence, such as when a loved one is missing physically but kept present psychologically because they may reappear. The second type of ambiguous loss, which many family members of brain injury survivors are faced with, occurs when there is a physical presence but a psychological absence (Boss, 2010).

Ambiguous loss can be experienced when a brain injury survivor no longer has the ability to function cognitively or even in cases where family members begin to notice that the survivor has had a change in personality as a result of the injury. In her study, Kean (2010) interviewed twelve adults and twelve children from nine different families. Each participant had a brain family member who had been in the intensive care unit following a brain injury for at least three days. The aim of the study was to explore common family experiences when dealing with the aftermath of a brain injury. Out of the nine families interviewed, Kean (2010) found that five participants reported feelings of ambiguous loss as a result of their family member having suffered a brain injury. These families expressed feelings of painful, immobilizing, and incomprehensible loss. The

insolvability of ambiguous loss is what makes it such a complex and challenging experience for all family members.

Domestic Partners & Spouses. Domestic partners who are in committed, intimate relationships with brain injury survivors frequently experience ambiguous loss. In Mauss-Clum and Ryan's sample of nineteen wives of men with brain injuries, half of the wives identified with the statement "I'm married but don't really have a husband" (Perlesz et al., 1999). Spouse caregivers face the challenge of living with someone who differs substantially post-injury as well as the adjustment to a marital relationship in which they may have to make decisions on behalf of their husband or wife with a brain injury (Degeneffe, 2001). Spouses tend to experience significant role changes; decreases in financial and parenting support; losses in sexual intimacy and empathetic communication with their partner; concerns about the children in the family; and little social opportunity to grieve these changes (Perlesz et al., 1999). Thomsen implemented a longitudinal research study that tracked relatives' responses to brain injury for up to twenty years. At a 10 to 15 year follow-up, Thomsen reported that seven of the nine couples in her sample had separated. She also found that the two couples that had not separated did not have children, which may suggest that extra burden is placed on couples that have children following a brain injury. It has also been found in numerous studies that brain injury has a more negative impact on spouses, rather than parents who have a child who has suffered a brain injury (1999).

Parents. Parents of brain injury survivors experience different concerns and challenges. Many face an extended parenthood, often at a stage when it is expected that parenting responsibilities should lessen (Degeneffe, 2001). Tarter explored the

adjustment of 48 parents of adult children who had suffered a traumatic brain injury, an average of 9.3 years following the incident of injury. Tarter found that behavioral impairment was a larger contributor to parental stress than physical disability. Parents are likely to struggle with negotiating issues of independence and dependence as their children recover (Perlesz et al., 1999). In a study conducted by Allen, it was found that parents caregiving for a child with a brain injury appear more concerned with the lifelong needs of the child whereas spouses reported significantly less personal reward in caring for a spouse with a brain injury (1999). One of the most common concerns of parents of brain injury survivors is concern about the child's long-term future. Parents may also experience extreme stress due to the fact that they may need to focus most of their time caring for the brain injury surviving child as opposed to being able to equally distribute their time between other family relationships (Degeneffe, 2001).

Siblings. Siblings of brain injury survivors often feel neglected by their parents who spend most of their energy caring for the injured sibling. Siblings tend to be isolated from both the patient as well as information during the acute hospitalization period, and they continue to be neglected in the long-term recovery (2001). Willer conducted qualitative research through a group discussion among seven siblings of an individual with a brain injury. The most significant family and personal problems reported by the siblings were concern about their injured sibling's future, high levels of family distress, changes in their family's lifestyle, barriers to their sibling's autonomy, as well as an increase in their own personal responsibility (Perlesz et al., 1999). Siblings may be asked to perform additional family chores and can often be expected to assume different roles within the family following the injury. Due to the fact that the sibling relationship is often

the longest family bond, the potential longevity of the caregiving role can be extensive and become a source of worry for the uninjured sibling. Orsillo determined that thirteen siblings of people with traumatic brain injuries showed significant levels of distress compared with individuals without a brain-injured sibling (Degeneffe, 2001).

Children. Children of brain injury survivors can also be faced with taking on additional family chores and expectations. Along with other family members, children who have a parent with a head injury may be called upon to take on a caregiving role or provide extensive assistance to the non-injured parent. Pessar observed twenty-four children of families in which one parent had a traumatic brain injury. Following the parent's injury, the children observed in the study demonstrated poor relationships with the injured parent, behaviors associated with acting out and emotional problems. Children often experience anger towards the injured parent because of the parent's potential embarrassing behavior and the disruption that the injury has caused within the family (Degeneffe, 2001).

Conceptual Framework

A review of literature on brain injury within a family system clearly demonstrates a family systems perspective to research. The review of literature on brain injury education, resources and support, as well as their availability to those who would benefit from them demonstrates an ecological systems perspective. The family systems theory as well as the ecological systems theory stem from the general systems theory, which states that a system must be understood as a whole and that a whole is different from the sum of its parts (Werner-Wilson, 2003). A system can be defined as "a set of elements that are

orderly and interrelated to make a functional whole” (Zastrow & Kirst-Ashman, 2010).

All systems have relationships with other systems, which they are interconnected with.

The largest type of system is a macro system, which may include a church, health care system, school or community. The second largest type of system is a mezzo system, which is moderately sized and may include work groups, social groups, or an individual’s extended family. The smallest systems are micro systems. Micro systems consist of immediate family members or significant others (Zastrow & Kirst-Ashman, 2010).

Members in all systems have roles to play within each system.

The Family Systems Theory

Families are considered systems because “they are made up of interrelated elements, they exhibit coherent behaviors, they have regular interactions, and they are interdependent on one another” (Morgaine, 2001). A family member who is a brain injury survivor is one of the “elements” of a family. In order to understand family behavior, this approach requires communication, transactional patterns, conflict, separateness, connectedness, cohesion and adaptation to stress within the family to be addressed (Fingerman & Bermann, 2000).

Stemming from the general systems theory, the family systems theory approach to understanding family life includes a collection of theories that are based in the field of family science as well as the field of mental health (2000). Family science has come to be affiliated with sociology, but also includes psychological, anthropological, economics and home economics perspectives on the functioning of a family. Professionals in the

mental health field recognize that psychotherapeutic changes in one member of the family system can bring on new problems for other family members (2000).

While only one member of the family may actually sustain the brain injury, the effects of that injury ripple throughout the entire family system. Family members are asked to take on different roles, adjust to a new family system that has a member who is either entirely missing from interaction or must interact differently, as well as deal with extreme stress. When examining to the experiences of family members of a brain injury survivor following a brain injury within the family, it is important to use a family systems perspective in order to view the entirety of the effects of the brain injury on the entire family rather than on the individual. In taking on this perspective better methods for developing and providing support and resources can be created.

The Ecological Systems Theory

The ecological systems theory allows for “respect for individuals’ and families’ capacities for effective coping” but also recognizes “the critical importance of environment—the physical and social contexts that support, constrain, and shape our efforts to live gratifying lives” (Lehmann, 2001). The ecological systems theory and approach was developed in order to aid professionals that are attempting to focus on person and environment when working with an individual, to have a truly balanced view that gives weight to both sides. Lehman further explains, “the purpose in formulating the ecosystems perspective was to encourage social workers to view systems holistically, attending simultaneously to people, their families, and whatever other systems might be important to their needs.”

While the ecological systems theory stems from the general systems theory, it also draws from the ecological theory as well. As previously explained, the general systems theory is important highlighting how interconnected we are as people within various social systems. Ecology is “the science that is concerned with the adaptive fit of organisms and their environments....Ecological ideas denotes the transactional processes that exist in natural and thus serve as a metaphor for human relatedness through mutual adaptation” (Lehmann, 2001). The ecological theory adds an emphasis on “goodness of fit”. Achieving a “goodness of fit” can be understood through considering demand factors in the environment and the resource factors in the environment. Our environment always places demands on us by presenting us with realities or stresses that require an adaptive response. In addition, our environment also provides us with access to resources. If there are adequate resources or availability to resources, one may adequately adapt to the demands and achieve a “goodness of fit” (2001).

Therefore, when both the general systems perspective and ecological concepts are combined, it allows for an understanding of how to achieve a “goodness of fit” with the use of various aspects of the environment (Lehmann, 2001). The ecosystems theory therefore examines the balance of supports and demands within systems. In order to gain a better understanding of the brain injury education, resources and supports that are currently available as well as those that are needed in order to aid brain injury survivors and their families, an ecosystems perspective should be used.

Methodology

Research Design

The research design of this study was exploratory qualitative, and involved semi-structured interviews. The information that was gathered for this research was obtained from family members of brain injury survivors who were at least one-year post injury. Semi-structured interviews provided structure with standard questions, but also allowed the subjects to expand on the questions and provide more personal data. A qualitative study provided the opportunity to hear the voices of family members of brain injury survivors and therefore allowed us to gain a better understanding of the informational, resource and support needs of family members during the first year following a brain injury.

Sample

The participants interviewed for this study consist of nine family members/caretakers of brain injury survivors who are at least one-year post-brain injury. These participants were present and involved in the life and recovery of their family member who sustained a brain injury. All participants were over the age of eight years old. These participants were gathered for this study through an availability sample. The participants were referred to this researcher through brain injury professionals within the community.

Protection of Human Subjects

Complete measures were taken to protect all participants who participated in this study as well as those family members that were spoken of. Included with the consent/assent forms was a complete list of questions that this researcher used in the interview, which the family received prior to completing this study. These documents provided all of the participants with full knowledge of the research that was conducted in order to reduce feelings of coercion when the interview took place. The participants were asked to sign an informed consent form (Appendix A1 & A2) prior to the start of the interview. At the beginning of each interview this researcher reminded the participants that it was okay to stop the interview at any time without any consequence or discouragement.

Throughout the data collection process, all data and records were kept in a secure and locked file cabinet in the researcher's home. At no point will has or will identifiable data be shared with anyone besides this researcher. Confidentiality was and is further being maintained by not writing participant's name on any research materials correlating with notes or information gathered from their interview. All identifiable information will be destroyed at the completion of this research, which will be May 24th, 2014.

There are risks involved with in this research. Some of the questions asked in the interview may trigger emotional issues or memories for the participants. Therefore, following each of the interviews, participants went through a debriefing with the researcher to be sure that they are leaving the interview with their emotional stability as close as possible to what it was when they entered the interview. During the debriefing, the researcher asked the participants how they felt about talking about all presented

subjects and about how they may feel later on during the day or the next few days. This researcher also provided the participants with contact information for the Minnesota Brain Injury Alliance, counseling centers as well as information regarding a support group for caregivers and family members of brain injury survivors in case they felt as if they need resources for support (Appendix E).

Data Collection

Participants who were referred to this study through professionals in the community had the professional inform them of this research project and then the participant contacted the researcher for further information. Other participants contacted this researcher for more information regarding the study after seeing a flyer (Appendix D) for the study posted on brain injury forums or throughout the community. Upon learning of the study, the participants contacted the researcher for more information. When the participants contacted the researcher, a script (Appendix F) was used to inform the participants about the study. Next, when the participants expressed continued interest in the study, a formal introduction letter (Appendix C), copy of the interview questions (Appendix B), as well as a copy of the consent form (Appendix A1 & A2) was sent to participants after they contacted the researcher. One to two weeks after sending out the letter of introduction, interview questions and consent form, the researcher followed up with the participants to schedule a time for the interview.

Interviews were conducted in person, when possible. They were conducted at agreed upon locations by both the researcher and participants. During each interview, the researcher presented each participant with a second copy of the interview questions and

reminded the participants of the purpose of the study, as well as the option to stop participating at any time. Each participant signed a consent form before each interview began. The data for this study was collected through 30 to 45 minute, semi-structured interviews, which were audio recorded for later data analysis. At the end of each interview, the researcher went through a debriefing process with each participant to ensure that when finished, each participant ended with their emotional stability as close as possible to what it was at the beginning. The research also provided each participant with a list of resources for support that included contact information different counseling services, a support group and the Minnesota Brain Injury Alliance (Appendix E).

Instrument

The instrument that was used for this study was a semi-structured interview. The questions that were asked in the interviews conducted centered around demographics, knowledge and awareness of brain injury, long-term effects of brain injury, the family's way of coping and adaptation, advice for others who have a family member that has recently suffered a brain injury, as well as additional necessary resources, supports and educational needs. These questions were used to identify themes in these specific areas.

Data Analysis

This study used a qualitative model to collect and analyze data. The researcher transcribed all data that was collected in the interviews. Once all of the interviews were completed and all of the data was collected, the researcher went through each transcription and used content analysis strategy to analyze the responses of the

participants. The researcher used open coding strategy to interpret data. After the coding was complete, the researcher identified themes that emerged from the data, sorted them into meaningful patterns and compared the results to previous studies and known information surrounding the topic.

Demographics

Nine participants were interviewed. Six participants (67%) of the participants were female and three (33%) were male. The different type of relationship that the family members who participated in this study had with the brain injury survivors in their families varied. The most common relationship found in the group of participants was a mother-child relationship. In this study four (44%) of the participants were mothers; three (33%) were spouses, one brother (11%), and one brother-in-law (11%).

The genders of the brain injury survivors related to the participants in this study were split almost evenly between male and female. Five (56%) of the related brain injury survivors were male and four (44%) of them were female. Out of the nine participants who were interviewed, six (67%) of the nine participants chose to reveal the age of their family member at the time that this family member's brain injury occurred. The age of the brain injury survivor at the time of incidence, in the six families who chose to provide this information, ranged from newborn/day of birth to fifty-six years old. The mean age was thirty-one years old. While three (33%) of the participants did not provide the age of their brain injury survivor family member at the time that the brain injury occurred, each of the three participants did indicate to the researcher through their other responses that all three of the brain injury survivors whose ages were not disclosed, were adults.

The range for the number of years that had passed since the brain injury occurred was one and a half years to thirty years. The mean length of time that it had been since the brain injuries occurred within this group of families was six years.

The most common type of brain injury that was reported by participants was traumatic brain injury. Eight (89%) reported that their family member survived a traumatic brain injury. One participant (11%) reported that their family member survived an acquired brain injury. Subjects were asked to disclose the cause of the brain injury. Four (44%) participants stated that the cause of the accident was a motor vehicle accident. Two (22%) participants report that the injury took place after being struck on the head by a tree. Three (33%) other causes listed by single participants were birth trauma, stroke and a free-boarding accident.

Findings

During this study participants were asked questions which facilitated the exploration of six different topic areas in order to gain an understanding of the participants' and their families' experience throughout the recovery process following the occurrence of a brain injury of a family member. Exploring these six topic areas also served the purpose of gathering the self-reported needs for resources, support, and education during the recovery process, from the participants. The six areas that were explored were: knowledge and awareness of brain injury, family/caregiver, long term effects of brain injury; the family's way of coping and adaptation, advice for others who have a family member that has recently suffered a brain injury, as well as additional

necessary resources, supports and educational needs. Within these four of these six topic areas that were explored in this study, themes emerged.

Knowledge & Awareness

Lack of General Brain Injury Awareness. When asked what they knew about brain injuries prior to a brain injury occurring within their family, four out of the nine participants (44%) stated that they knew nothing at all about them. Four of the other remaining five participants stated that they knew a little bit about brain injuries. When those four were asked to describe what specifically they knew about brain injuries, none of the four who reported that they had known a little bit about brain injury prior to their own family's experience could list any valid or specific facts about brain injury. Some of their responses included:

...just that I had a friend at work whose aunt had a similar injury and was hospitalized for awhile. But that's really all I knew, that someone I knew, knew someone who had one.

I only knew that soldiers got them a lot. But news stories focused only on the really serious ones where people were immediately unresponsive. Then other than hearing that someone had a head injury and was unresponsive, I never really heard anything else. The stories don't ever follow the injury all the way through.

When I was in high school an adult friend of my family took a fall from a ladder while clearing out roof gutters at his parent's home. He had severe brain trauma. He survived another 35 years but ended up living in a customized home under 24 hour care.

Overall, eight (89%) participants in this study were unaware of what exactly brain injury was, and had very little to no information on long term effects prior to their family's experience. The participants in this study were asked questions to determine

when along the path of recovery they were provided with general educational information on brain injuries by professionals at different levels of care. All nine (100%) participants shared that throughout their experiences they received very little to, no brain injury education. Some of the family members/caretakers responded:

Unfortunately we were only given information about brain injuries the day my husband was transferred to the sub-acute facility. The sub-acute care facility had very little useful information, although they were very supportive. Inpatient rehabilitation offered no useful information.

At the first hospital I didn't receive anything. He was transferred to an LTACH where he woke up from his coma. I received a few answers to questions about further rehab care, but that was it.

No information was ever given to me by my doctor, the hospital or the schools...

Misdiagnosis. While discussing the brain injury that occurred within their family, four (44%) participants mentioned that the first time that their family member sought medical attention following the brain injury; the injury or the severity of the injury was misdiagnosed. One of the participants discussed how even though her child's brain injury occurred in the hospital, due to birth trauma, her brain injury was not diagnosed until her daughter was in junior high. This participant stated,

I wasn't even told that there was a possibility that she had sustained a brain injury. She was only tested for hydrocephaly at birth, though she was in the ICU for a week. We knew something was wrong with her nearly from the time we brought her home. The next-door neighbor had a child born the same week and my daughter was significantly behind in her development compared to him. We didn't get confirmation that it was actually a brain injury until our daughter was in junior high and one of her teachers recognized it in her because the teacher had had a child in a car accident that sustained a brain injury and recognized the changes in personality and abilities. [Child] was then tested and found to have multiple indicators of a TBI.

Another participant told the story of her child's brain injury which occurred when a dead tree fell and hit her daughter on the head while a group of children were messing around with the trees attempting to show how strong they were. The participant's child was immediately taken to the emergency room where she was diagnosed with a concussion and released with instructions to rest for a few days. A few days later when her child was still not feeling better the participant brought the child to see a neurologist. The neurologist provided the family with information on concussions and how they relate to high school athletes and she was released without further appointments. During the thirteen months that followed the participant reported,

Her personality had made a 180-degree turn for the worst. Things she had loved doing, she suddenly hated. Impulsive behaviors started to bring about consequences she had never dealt with. Rules no longer applied to her. Her memory was still making school hard. She had been a 4.0, advanced placement honor student in addition to being a multi-sport athlete in a large high school. Her social skills had disappeared, affecting every friendship that she ever had in negative ways. During this time we had to assume that these were the nasty teenage years that everyone talks about. After all, she had been released by the emergency room as well as the neurologist and shouldn't they know if there was brain damage or a need for further examination?

After thirteen months had passed and the participant reported that her child's personality had changed so drastically in such negative ways, the participant returned to the neurologist and demanded that an MRI be run. The participant stated, "I realized that things were just too much of the exact opposite of who she had been for it to simply be the teenage years". The MRI that was done thirteen months after the participant's daughter had been brought to the emergency room showed that the child had sustained brain damage. The participant explained, "The MRI was run in September. Of the seven sections of her brain, it showed only one functioning at the 'normal level'. Three were

low, and three were near dormancy...I'm not sure we ever would have found out what was going on if I hadn't insisted."

Another participant reported that the severity of her husband's brain injury was not accurately diagnosed or looked into thoroughly by the emergency department. The participant's husband was also involved in a motor vehicle accident and was conscious when he was brought to the emergency room following the accident. The emergency department released him without completing an MRI or CT scan and informed the participant and her husband that it was just a concussion and that he needed to rest. The participant stated, "But as time went on and major symptoms were coming up we made our way back to the doctor for more answers. The doctor informed us that he must have post-concussion syndrome and that he would need about six months to heal." As symptoms continued to worsen the participant brought her husband to multiple neurologists who all sent them away to "heal from post-concussion syndrome." Eventually, one year and nine months after the accident the participant and her husband saw a new neurologist. This neurologist completed the survivor's first MRI following the accident, which showed significant damage to his brain.

Family/Caregiver Effects

Stress & Change in Roles. All of the participants (100%) expressed significant stress and change in their family roles following the occurrence of the brain injury.

Participants explained,

It was really stressful for everyone. We were stressed out because we didn't know what was going to happen, if he was going to make it or how much he would recover. We were stressed about finances and were all missing a lot of work.

All of it was exhausting. I had to be on all of the time...to talk to nurses and doctors, to talk to other family members and friends who wanted updates. I had to give nearly all of my time to being where he was. I had to rely a lot on my oldest kids to take care of things at home and to be able to take care of themselves and each other.

Lack of Caregiver/Family Effects Information & Resources Provided. While all nine (100%) of the participants reported that the brain injury of a family member affected others in the family aside from the survivor themselves, none of them received information on how family members were affected by a brain injury. As some participants included:

Nothing really. One nurse at first told me to make sure that I got rest and nutrition because the real work begins after you and the patient get home.

Frankly, I don't recall any such literature or information being given to me. I observed a lot of compassionate professionals who were very busy but supportive and complimentary of my family members, acknowledging the fatigue, trauma, and changes they were championing through. But I do not recall any information on family effects being provided.

None. We had to ask and search on our own as we lived through what we now know to be the common family outcomes and effects of a brain injury within the family.

Participants were asked to discuss any family support resources that they were provided from outside agencies. Seven (78%) participants replied that they were provided with little to no family support resources during recovery. As one participant stated:

Honestly, none. All I have found thus far, has been because of our own work in seeking out support for our family or things that family friends have recommended to us.

Another participant stated:

Very little. I contacted the Brain Injury Association of America who offered some moral support. Through contacting them I found a local TBI group. However, that was not very helpful because most of the attendees were high functioning survivors or had family members who were high functioning survivors. We again felt the uniqueness of his TBI isolating.

Two (22%) participants noted that they did receive resources. One participant explained that he had been given information on a weekly, joint support group for brain injury survivors and their family members early on in the recovery process. Another participant noted that she was provided with information on a support group for family members of brain injury survivors. This participant explained that she also was given information on the yearly state brain injury conference, as well as the classes provided at the conference by the Brain Injury Alliance in her state.

Long Term Effects of Brain Injury

Lack of Information Provided. Participants were asked what information they received on potential long-term effects of brain injury. Nine (100%) participants expressed that they did not believe that they were provided with nearly enough information. They agreed that even less information was provided on the potential effects of brain injury that can be long lasting or late to occur, especially those that are not physical effects. Two (22%) participants stated that the most specific information given about the long term effects of a brain injury was in mentioning specifics about physical limitations and reinforcing that things may never be the same. These two participants discussed limitations by stating:

Other than just hearing that it might take some time before the strength on his right side gets back to where it was, I don't recall hearing or having any literature provided relevant to any emotional or psychological counseling that might be needed in the long run.

We were told that we could expect that things would never be the same as they were before he accident but that we could try to create a new normal.

Only two (22%) participants reported being given educational literature as an attempt to provide information on potential long-term effects of brain injury. One participant reports:

We were just given some general pamphlets that listed some effects of brain injuries and common resources. Not a lot, that's for sure. That is one area where all hospitals can improve.

The other participant reported that the literature that they received was not brain injury specific:

When I asked for information on what we could expect long term, or moving forward, I was given five or six booklets about older people with physical disabilities or about those who aren't able to talk. I also was given some American Heart Association recipes that I would never make. My wife was thirty-eight years old and had cognitive deficits from a brain injury.

Five (56%) participants stated that the potential long-term mental and emotional effects of brain injury were never mentioned to them throughout their family member's recovery process. One participant concurs with this when she states:

We weren't ever told about the increased risk for depression and anxiety after brain injury. No one gave us any information and no one explained to us just how challenging it could be for a brain injury survivor emotionally to deal with the reality of who they are now. We had not dealt with this before, we did not know what to expect. We were just happy he was alive and that he appeared to be fine.

Another participant explains their experience:

I only found information on mental and emotional effects through my own research. Nothing was mentioned to anyone in my family on what internal

struggles could come. I had no idea that a TBI could change someone's personality.

Nine (100%) of the participants reported that they did not receive enough information about brain injury. Six (67%) subjects reported that they received no information. Three (33%) of the participants stated that they received information on potential the mental health effects. One of those three participants stated that, "Depression was mentioned, personality change, and loss of memory. But it was in the booklets I was given, not mentioned in person." Two of those three participants state that the information that they received was brief and unhelpful. The two participants explain:

Basically, I wasn't told much...just that anxiety and depression can be common side effects and that I should seen counseling for my husband and myself if I feel we need it.

One doctor mentioned briefly that depression is fairly common after an injury of this type and he prescribed an anti-depressant, which we later found out that [brain injury survivor] was making us think she was taking but really wasn't.

Emotional & Mental Health Effects. In discussing the participants' experiences with the challenge of facing long-term effects of brain injury especially after not having received sufficient information on potential effects, six (67%) participants expressed that the brain injury survivor in their family has experienced emotional and mental health effects following the brain injury. The six participants agreed with that the emotional and mental health effects have been the most challenging to come to terms with for the brain injury survivor and the rest of the family. Some of the instances and results of emotional and mental health effects experienced within these families as a result of brain injury include: depression, anxiety, PTSD, complete change in personality, substance abuse, anger problems, memory loss, and behavioral issues. One participant mentioned within

the interview that the brain injury survivor in his family committed suicide two years following his brain injury. Some of the participant's responses include:

We thought he would keep healing naturally, which he did in some ways. What we did not expect were his behavioral problems. We discovered that the Seroquel they had been giving him for most of his stay had suppressed his temper, a temper that he did not have prior to the TBI. He did not like the medication either, and we felt it was hindering his cognitive skills, but we had no idea how much it was controlling him. We had no idea we had this new person who could not really be reasoned or argued with, there was no winning.

My brother is unaware that his personality has changed. His tastes even changed. Family and friends know it is not him anymore, but he does not. He cannot. He is gone, yet he is not gone, and worse he is now terribly selfish, insensitive, short of temper, stinky from not taking care of himself...my brother used to have a wicked sense of humor but I have not heard him more than half-chuckle once or twice in more than two years.

She has had anxiety throughout her whole life, ever since her brain injury. She wigs out when things change. She recently has developed severe depression and luckily is getting help with it.

He has been severely depressed, spending lots of money on crazy new hobbies, coming up with all kinds of ways to leave town with conferences and not to go to work. Then getting off schedule at work and showing up late. He has had an awful time even telling me he likes me, forget loves me...it seems like emotionally, he died and its going to be an 8-10 year recover for him. Luckily I'm in it for the long haul with him.

All of the participants (100%) expressed that information on the long-term, mental and emotional effects of brain injury need to be more widely available. All participants also agreed that brain injury awareness, especially as it relates to mental health needs to be increased within all aspects of society. Participants stated:

I would say the biggest frustration for [brain injury survivor] was the fact that there was no showing evidence of any injury, so [brain injury survivor] felt that people didn't take it seriously because she "looked fine." She had to try to return to school but didn't feel well. The lights and noise levels at assemblies were just crushing. She would leave in tears and her friends would think she was crazy when in reality those things really did hurt her. She felt very much that if she had

been in a cast for a broken leg or if there had been some physical evidence of injury, people would have been much more aware of the fact that she was still healing.

Overall we feel like there is a permeating lack of awareness about the true outcomes of brain injury. Especially as it relates to mental health. I know we definitely fell into that category before living this. Even now, 20 months later, people will comment on how great our daughter is doing and how well she has recovered. And by all outward appearances that seems to be the case. But only by living and knowing the path and the intimate changes that have occurred and continue to occur are we aware of how far she still has to go.

Coping & Adaptation

Family Support. Four out of the nine participants (44%) mentioned the importance of receiving family support to help them cope and adapt. They agreed that it was from the support of their family members that they were able to make it through such a challenging time. Participants reported:

We became unified. This isn't a way we would have chosen to live before all of this happened. But we have become closer and more unified in our thoughts and actions, as we have had to help each other and our family adapt and cope.

I feel the only way we survived this was the fact that neither of us were single parents trying to deal with this on our own. My husband and I have been married 24 years, and we coped and adapted by taking turns carrying the load and responsibilities and giving each other breaks.

Developed Strengths. Seven (78%) participants stated that they developed at least one strength from the new challenges that they were forced to face. The common strengths mentioned by participants were: patience, faith, empathy, determination, the ability to advocate, and unconditional love. Participants explained their acquired strengths:

I learned how to empathize much more with people. We don't know their stories any more than they know ours. We are so much slower to make judgments about people or their situations now.

Going through this forced me to learn a lot about patience and unconditional love. I can deal with very hard things now without falling apart, such as a recent bout with breast cancer, because of the strengths I developed to get me through the hard times we had after her injury.

I had to be patient and I certainly learned how to be. I also learned how to better control my temper. Both of those still help me out today and if I wouldn't have been able to get those out of the situation, I don't think I would have made it through. Or at least made it through in one piece.

Two (22%) participants expressed specific strengths that they developed in order to help them and their family cope and adapt throughout the recovery process. Some of their responses included:

I helped out with [brain injury survivor]'s personal and business matters and took on more responsibilities at home. That helped me feel like I could at least control something...I also had to learn that we all have to learn to look forward with our lives while focusing on the best of our memories. Otherwise it will consume our own energy and lives. Then our own mental, emotional and physical health is threatened as well.

I had to finally come to understand that what doesn't kill you, makes you stronger...in some ways. Not long ago my mother was diagnosed with early onset Alzheimer's. Had I not gone through the TBI with my brother, I do not think that I could have faced the Alzheimer's. Now there is acceptance and a sense of knowing there is not a lot that I can do. I know that I have limits and that I must balance taking care of Mom with my family.

Advice for Others

Participants were asked what advice they would give to a family member of someone who had just sustained a brain injury. Six (67%) participants responded with advice involving the importance of having patience throughout recovery. One participant simply said, "It is important to have hope, and a lot of patience as well. It is a long road."

Another participant whose advice centered around the importance of patience explained, “Be patient, just take it one day at a time. Celebrate the little victories.” While a majority of the pieces of advice provided by the participants stemmed from the importance of having patience, three participants provided specific pieces of advice. The participants’ advice is:

Get your family into brain injury support groups immediately. Study the Internet for more information and employ a professional health care agency to provide respite care for the family, and to coordinate the flow of information early on in the process as it is simply overwhelming to traumatized family members.

Think of TBI recovery in years, not months. Very little is in your control. Accept them for who they are on that particular day. Meet them where they are at and try not to project who they were on the person they are today. Learn to control your responses. You cannot control how far they will recover.

Know that life won’t be the same as before the accident. As sad and as heartbreaking as that it is. But it can be a good life. You have to create a new normal. Learn to laugh and find joy in small things. Know that you will probably have lots of terrible days but try to start with having a good hour. Let the small things go.

Needed Resources

Throughout the interview all of the participants expressed their beliefs that there needs to be more brain injury education, more resources with, better access, and an increased awareness of available resources through the communication of professionals who interact with brain injury survivors and their families. Seven (78%) participants acknowledged that they had either participated in support groups which they found to be helpful and/or that they wished there were more support groups available for both brain injury survivors as well as their family members. Three (33%) participants expressed the need for more mental health professionals who understand the complexities of brain injury. One of those participants stated:

As we slowly learned, recovering from brain injury and adjusting to life afterwards is a long process for both the sufferer and the family. We sought out counseling once as a family. Yes, I guess you could say that it was nice to talk to someone not involved, about what was going on and all of the grief and changes. But the therapist did not have an understanding of the complexities of brain injury. We felt like we spent most of the sessions explaining how this grief we feel, feels so much different than any death or loss we experienced before.

One of the participants mentioned that she would like to see brain injury information and support tailored towards helping children understand brain injury more widely available and offered by professionals. The participant stated:

Some families are not lucky enough to have two parent households. What if a single mother suffers a brain injury? Are there supports for her children? Even if the family is lucky enough to have two parents involved, it is hard to explain to a child why their mom or dad is suddenly different. I know now that there are resources out there that can help. But I wish I would have known about them a lot earlier.

Another participant discussed that she wished there were more social venues for young adults who have suffered a brain injury so that they could have a chance to interact with individuals around their own age who are going through similar struggles.

Nine (100%) participants mentioned that their needs to be a greater effort to provide families with brain injury education on the injury and the effects of the injury earlier on in recovery, and most certainly before the brain injury survivor returns home. Eight (89%) of the participants mentioned that more information is needed to be available to the general public and awareness of brain injury and its effects within the community needs to be increased. One of the participants expressed his feelings on brain injury awareness,

I think popular culture is ignorant of TBI because it is such an obscene, personal tragedy. Yet different in every case. It would not play well on TV or movies. No family member would dare let their loved one be exposed in such a manner along with so much intense grief. On top of that, it would not make sense unless the

documentary had a deep grasp of the victim before the TBI. But the public needs to know.

Discussion

Summary of Findings

The interviews conducted looked to gain an understanding of the participants' and their families' experience throughout the recovery process following the occurrence of a brain injury of a family member. During the interviews the self-reported needs for resources, support, and education during the recovery process, from the participants were collected.

The participants' responses within this study were congruent with the formerly discussed lack of general brain injury awareness. As previously stated, only one in three Americans are familiar with the term "brain injury" resulting in a lack of public knowledge surrounding both acquired and traumatic brain injuries. (University of Pennsylvania Center for Brain Injury and Repair). It was clear within this study that participants had no knowledge or very little knowledge about brain injury prior to a brain injury occurring in their families. Four participants reported that they knew nothing about brain injuries prior to one occurring within their family. Another four participants had only a little knowledge surrounding brain injuries but were unable to provide any facts or specific information surrounding them.

Not only was a lack of brain injury awareness found within the participants of this study, but there was a high occurrence in this group of participants of misdiagnosis of brain injuries by medical professionals. The prevalence of participants who experienced misdiagnosis of a brain injury within their family is consistent with the previously

discussed high number of undiagnosed and misdiagnosed brain injuries. Quinn (2002) reports that there are 1.5 million brain injuries that occur within the United States each year and of those 1.5 million brain injuries that occur, 1.1 million are treated and released from the emergency department without further testing.

All of the participants in this study reported that they felt the effects of the brain injury throughout the entire family. This finding is consistent with all research, which shows that brain injury can have a wide range of effects that often ripple across the entire family. In fact, family and caregiver effects of brain injuries are so prevalent among families touched by brain injury that the Brain Injury Association of America (2009) has identified six stages of adjustment that families go through following a brain injury of a loved one. In some capacity all of the participants mentioned feeling extreme amounts of stress. They felt stress due to not knowing what the future held for the brain injury survivor and they were financially stressed as well. Due to the fact that so much of the participants' time was being spent with the brain injury survivor, as well as the fact that the family member who sustained the brain injury survivor could no longer function in the family role that he or she once held, there were changes in family roles. Within the research, both the increased levels of stress, and the change in family roles are listed as common family effects of brain injury (Perlesz et al., 1999).

While all of the participants reported experiencing effects of the brain injury throughout their entire family, the participants as a whole did not report having received any educational information on the possible caregiver/family effects of brain injury. Out of the nine participants who reported receiving no information on the effects that a brain injury can have on the family and caregivers, four mentioned that the effects on their

family were so noticeable that they felt the need to do research on the family and caregiver effects themselves.

Participants identified that there is a lack of information provided by professionals on the long-term effects of brain injury. Each participant explained that they ended up completing research on their own. All nine participants reported that they received little to no information, resources or education from professionals. Participants also stated that they received very little information on the emotional and mental health effects of a brain injury. The participants identified depression, anxiety, PTSD, complete change in personality, substance abuse, anger problems, memory loss, behavioral issues and suicide as being aspects of the long-term emotional and mental health effects that their family members has experienced. These reports of different emotional and mental health effects of brain injury are consistent with the common effects of brain injury in the research and consistent with the fact that many of the emotional and mental health effects are long term. Yates (2008) states that at twelve months following the occurrence of a brain injury, it is the behavioral and cognitive consequences that appear most prevalent and can have potentially devastating social implications for the survivor leading to increased feelings of loss of self and social isolation.

Limitations of the Study

There were nine family members of brain injury survivors who participated in this study. Therefore, due to the small sample size of this research study, the experiences and opinions of the participants cannot be generalized to all family members of brain injury survivors. The participants included in this study learned of the project through brain

injury professionals within Minnesota or contacted the researcher after finding a flyer for the study posted online on brain injury forums. Therefore, the participants in this study do not represent the views of family members of brain injury survivors throughout the entire country.

The questions that were asked during the interviews were asked with the intention of gathering information on the time period immediately following the brain injury that occurred within the family. The time following the brain injury of a family member is recognized as being a state of crisis and shock. Therefore, a limitation of this research is that the researcher at times, asked the participants to recall information or experiences from a time in which they were very overwhelmed. Research has shown that over-secretion of stress hormones adversely affects brain function, especially memory. During a time of crisis, the adrenal glands immediately release adrenalin. If the state of extreme stress or crisis persists after a couple of minutes, as it likely will following being informed that a family member has sustained a brain injury, the adrenals then release cortisol. Cortisol remains in the brain much longer than adrenalin, and it continues to affect brain cells. Cortisol can interfere with the function of neurotransmitters or the chemicals that brain cells use to communicate with each other (Franklin Institute, 2004). Therefore, the brain's reaction to extreme stress such as the stress that one experiences following the brain injury of a family member, may prohibit someone from absorbing any information provided to them by professionals that this researcher asked them to recall during the interview.

Social Work Implications

In the United States, each year an estimated 1.5 to 2 million people sustain a traumatic brain injury. Of those 1.5 to 2 million people, 70,000 to 90,00 people will experience long-term functional impairments as a result of the injury, and around 50,000 individuals will not survive the first year following the injury (Degeneffe, 2001). These high numbers of individuals who have sustained a brain injury are mind blowing, and they do not even include the family members and friends of survivors who are impacted by the brain injury of a loved one. With so many Americans affected by brain injury each year, there is a lot of need for social work support and advocacy surrounding the topic.

This study showed that there is a need to increase brain injury awareness in the general public, especially surrounding topics of mental health and long-term effects. Social workers have the ability to work with community organizations to spread awareness of brain injury. The participants in this study also shared information through their experiences on the lack of information on brain injury, the effects and the family/caregiver effects that is being provided by professionals throughout the recovery process. At nearly every facility that a brain injury patient will spend time at during the recovery process, there is a social worker who is employed. Social workers who are employed at these facilities have the ability to work to fill these gaps between existing educational information and resources, and the educating of the survivor and their family.

The importance of brain injury specific support and resources was also expressed through the stories of the participants involved in this study. There is a need for brain injury specific support groups for both brain injury survivors as well as their family members. More community programs could be created to help brain injury survivors and

their families with community reintegration, and forming connections with other survivors and families who have had similar experiences. These programs will be of great importance as our soldiers continue to return home from combat in Iraq and Afghanistan with brain injuries and the awareness and diagnosis of those with sports related concussions and brain injuries increases. Due to the statistic that 40% of those who have endured a traumatic brain injury suffer from two or more psychiatric disorders, the inclusion and availability of mental health specific information and resources within these programs for brain injury survivors and their families is essential (Vaishnabi, 2009).

Conclusion

This research study asked family members and caretakers of brain injury survivors to provide their personal experiences surrounding accessibility, helpfulness, and the effects of the brain injury educational information, resources, and support that they received from professionals during the recovery period, post injury. The findings of this research study revealed a lack of brain injury educational information, resources and support made available to the families of brain injury survivors following a brain injury. The study also suggested a strong need for increased educational information, resources and support as well as a wider availability and distribution of resources and brain injury education following a brain injury. The participants in this study shared their experiences following the brain injury of a family member, which highlighted the prevalence of the cognitive and emotional long-term effects of brain injury and the need for mental health resources and education.

Due to the large number of Americans who are affected by brain injury either personally or through relation to a family member, it is essential that the amount of and availability of educational information, resources and support be increased. As soldiers continue to return from combat in Iraq and Afghanistan with head injuries, and with the advancement of medical technology allowing more and more individuals to survive a brain injury, social workers as well as all medical and social service professionals will continue to have more involvement with brain injury survivors and their families.

References

- Allin, M. & Fleminger, S. (2006). Acquired brain injury. In. G. Roberts, S. Davenport, F. Halloway, T. Tattan. (Eds.). *Enabling recovery: The principles and practice of rehabilitation psychiatry*. (325-338). Belgrave Square, London: The Royal College of Psychiatrists.
- Boss, P. (2010). The trauma and complicated grief of ambiguous loss. *Pastoral Psychology*. 59: 137-145.
- Bryant, C.D., & Peck, D.L. (2009). Ambiguous loss & unresolved grief. *Encyclopedia of Death & the Human Experience*. Vol. 1.
- Brumback, R.A. (1996). *Neurology and Clinical Neuroscience*. Oklahoma: The University of Oklahoma College of Medicine.
- Buck, W. (2011). Mild traumatic brain injury: a silent epidemic in our practices. *Health & Social Work*. 36, 299-302.
- Cabezas, F. (2001). Neurobehavioral and Cognitive Profile of Traumatic Brain Injury Patients at Risk for Depression and Suicide. *Brain Injury*, 15(2): 175-181.
- Churchwill, J. (2011). Neuroimaging Correlates of Traumatic Brain Injury and Suicidal Behavior. *Head Trauma Rehabilitation*. Jul-Aug; 26(4): 276-89
- Cloute, K., Mitchell, A., & Yates, P. (2008). Traumatic brain injury and the construction of identity: a discursive approach. *Neuropsychological Rehabilitation*. 18(5/6): 651-670.
- Degeneffe, C. E. (2001). Family caregiving and traumatic brain injury. *Health & Social Work*, 26(4), 257-268.
- Federoff, J., Starkstein, S., Forrester, A., Geisler, F., Jorge, R., Arndt, S., & Robinson, R. (1992). Depression in patients with acute traumatic brain injury. *American Journal of Psychiatry*. 149(7).
- Fingerman, K. & Bermann, E. (2000). Applications of family systems theory to the study of adulthood. *International Journal of Aging and Human Development*. 51 (1).
- Finnie, J., & Blumbergs, P. (2002). Traumatic brain injury. *Veterinary pathology online*. 39:679-689.
- Fleminger, S. (2010). Neuropsychiatric Effects of Traumatic Brain Injury: Secondary Symptoms You Need to Watch For. *Psychiatric Times*. 27 (3).

- Franklin Institute. (2004). The Human Brain. "Stress and Memory".
<<http://learn.fi.edu/learn/brain/stress.html#stressmemory>>
- Ghajar, J. (2000). Traumatic brain injury. *The Lancet*. 356, 923-929.
- Iskander, D., Cohen, A., & Kapoor, N. (2010). Optometric management of a patient with parietal lobe injury. *Journal of Behavioral Optometry*, 21(Volume 2).
- Kean, J, P. T., Murray, L. L., Abell, M. & Trexler, L. E. (2010). Initial validation of a brief provisional diagnostic scale for delirium. *Brain Injury*, 24, 1222-30
- Landau, J., & Hissett, J. (2008). Mild traumatic brain injury: Impact on identity and ambiguous loss in the family. *Families, Systems, & Health*. Vol 26(1), Mar 2008, 69-85.
- Lehmann, P. (2001). Theoretical Perspectives for Direct Social Work Practice: A Generalist-Eclectic Approach. New York: Springer Publishing Company Inc.
- Maas, A., Stocchetti, N., & Bullock, R. (2008). Moderate and severe traumatic brain injury in adults. *The Lancet*. 7, 728-741.
- Marar, M., McIlvain, N., Fields, S., & Comstock, D. (2012). Epidemiology of concussions among United States high school athletes in 20 sports. *The American Journal of Sports Medicine*. 40 (4), 747-755.
- Mason, M. P. (2008). Head cases: Stories of brain injury and its aftermath. New York: Farrar, Straus and Giroux.
- Middelkamp, W., Moulaert, V., Verbunt, J., Van Heugten, C., Bakx, W., & Wade, D. (2007). Life after survival: long-term daily life functioning and quality of life of patients with hypoxic brain injury as a result of a cardiac arrest. *Clinical Rehabilitation*. 21, 425-431.
- Morgaine, C. (2001). Family Systems Theory.
<<http://web.pdx.edu/~cbcm/CFS410U/FamilySystemsTheory.pdf>>
- Perlesz , A. O'Loughlan , M. (1998). Changes in stress and burden in families seeking therapy following traumatic brain injury: A followup study. *International Journal of Rehabilitation Research*, 21, 339-54.
- Ponsford, J. & Fleminger, S. (2005). Long term outcome of traumatic brain injury. *British Medical Journal*. 331(7530): 1419–1420.
- Strandberg, T. (2009). Adults with acquired traumatic brain injury: Experiences of a changeover process and consequences in everyday life. *Social Work in Health Care*, 14(12), 276-293.

- Saout, V., Gambart, G., Leguay, D., Ferrapie, A. L., Launay, C., & Richard, I. (2011). Aggressive behavior after traumatic brain injury. *Annals of Physical and Rehabilitation Medicine*. 54, 259-269.
- Simpson, G. & Tate, R. (2002). Suicidality after traumatic brain injury: Demographic, injury, and clinical correlates. *Psychological Medicine*, 32, 687–697.
- The Brain Trauma Foundation. TBI Statistics. “Facts About TBI in the USA.” Web. 9 Dec. 2012. < <https://www.braintrauma.org/tbi-facts/tbi-statistics/>>
- University of Pennsylvania Center for Brain Injury and Repair. “Traumatic Brain Injury: A Silent Epidemic.” Web. <https://www.med.upenn.edu/cbir/silent_epidemic.shtml>
- Vaishnabi, S., Rao, V., Fann, J. (2009). Neuropsychiatric Problems After Traumatic Brain Injury: Unraveling the Silent Epidemic. 50(3). 198-205.
- Van Zomeren, A. & Van Den Burg, W. (1985). Residual complaints of patients two years after severe head injury. *Journal of Neurology, Neurosurgery, and Psychiatry*. 48:21-28
- Wasserman, L., Shaw, T., Vu, M., Ko, C., Bollegala, D., & Bhalerao, S. (2008). An overview of traumatic brain injury and suicide. *Brain Injury*. 22, 811-819.
- Werner-Wilson, R. J., Michaels, M. L., Thomas, S. G., & Thiesen, A. M. (2003). Influence of therapist behaviors on therapeutic alliance. *Contemporary Family Therapy*, 25, 381-390.
- Williamson, D. J., Scott, J. G., & Adams, R. L. (1996). Neuropsychology for clinical practice: Etiology, assessment, and treatment of common neurological disorders.
- World Health Organization. *Violence and Injury Prevention and Disability (VIP)*. “Neurotrauma.” Web. 2014. <http://www.who.int/violence_injury_prevention/road_traffic/activities/neurotrauma/en/>
- Zastrow, C.H., & Kirst-Ashman, K.K. (2010). *Understanding human behavior and the social environment*. (8th ed.) Belmont, CA: Brooks/Cole Cengage Learning.

Appendix A1

CONSENT FORM UNIVERSITY OF ST. THOMAS

Self-Reported Needs of Family Members/Caregivers of Traumatic Brain Injury Survivors

I am conducting a study about the self-reported brain injury education information, resource & support needs and experiences of family members/caregivers of brain injury survivors during recovery. You were selected as a possible participant because you have been identified as a caretaker of a family member who is a brain injury survivor. Please read this form and ask any questions you may have before agreeing to be in the study.

This study is being conducted by: Katelyn Ryan, a graduate student at the School of Social Work, St. Catherine University/University of St. Thomas and supervised by my faculty chair Colin Hollidge P.h.D., LICSW and two professionals from the community.

Background Information:

The purpose of this study is to gather information on what brain injury educational information, resources, and support are necessary for professionals to provide for family members and caregivers of a brain injury survivor throughout the initial recovery process as well as to look at the personal experiences of family members and caregivers surrounding accessibility, helpfulness, and effects of information, resources, support and interactions with professionals. The research results from this study will provide social workers with a greater understanding of the needs of family members and caregivers, appropriate timing for presentation of educational information and resources, as well as to help identify the current gaps in providing brain injury education and support.

Procedures:

If you agree to be in this study, I will ask you to allow me to interview you at a location of your choice. The interview will be audio-taped and will take about forty five minutes of your time.

Risks and Benefits of Being in the Study:

This study's single risk is discussing a serious topic, which may provoke difficult memories or strong emotions in regards to your experience with a family member who is a brain injury survivor. To minimize the risk, if at any point during the interview you feel you cannot continue, the interview will cease and I will stay with you to ensure your stability and well-being, until you are feeling better. A short debriefing will also take place at the end of every interview if you should choose to participate. Contact information for support resources such as the Minnesota Brain Injury Alliance, Crisis Connection, C.O.P.E., Walk In Counseling Center, as well as information regarding support groups for family members and caretakers of brain injury survivors is being provided to you along with this form and will again be provided to you during the interview if you choose to participate. The study has no direct or known benefits.

Appendix A2

Confidentiality:

The records of this study as well as signed consent forms will be kept confidential. In any sort of report that I publish, I will not include information that will make it possible to identify you in any way. Research records will be kept in a locked file cabinet in my home office and I am the only person who will have access to the records. The audiotape will be used solely to conduct this study and will not be presented elsewhere. Any and all identifying information from the taped interview will be deleted. The audio recording will be destroyed at the completion of the research, which will be no later than May 24th, 2014. The transcripts and consent forms will be kept indefinitely in my home office and may be used for further educational purposes only. There will be no identifying information on the transcripts.

Voluntary Nature of the Study:

Your participation in this study is entirely voluntary. You may skip any questions you do not wish to answer and may stop the interview at any time. Your decision whether or not to participate will not affect your current or future relations with St. Catherine University, the University of St. Thomas, or the School of Social Work. If you decide to participate, you are free to withdraw at any time up until April 9th, 2014. Should you decide to withdraw, data collected about you will not be used.

Contacts and Questions

My name is Katelyn Ryan. You may ask any questions you have now. If you have questions later, you may contact me at (651) 271-6738. You may also contact my instructor and research chair, Colin Hollidge at (651) 336-1506. You may also contact the University of St. Thomas Institutional Review Board at (651) 962-5341 with any questions or concerns.

You will be given a copy of this form to keep for your records.

Statement of Consent:

I have read the above information. My questions have been answered to my satisfaction. I consent to participate in the study and to be audiotaped.

Signature of Study Participant

Date

Print Name of Study Participant

Signature of Researcher

Date

Appendix B

Interview Schedule

What is your relationship to the individual with a brain injury?

How did the injury occur?

How long ago?

Prior to the event what did you know about brain injuries?

Where had you learned anything that you knew?

What brain injury education and/or resources were you provided with throughout out your family members recovery?

What information were you given/what were you told about brain injuries at the first hospital?

What information were you given/what were you told about brain injuries at the second hospital/long term acute care hospital? (if applicable)

What information were you given/what were you told about brain injuries at the rehab facility? (if applicable)

What information were you given/what were you told about brain injuries during outpatient rehab? (if applicable)

Who gave you this information?

What were you told to expect about moving forward with the recovery when the time came to return home?

What resources/information were you provided with that discussed long term effects/common long-term struggles with returning home following a brain injury?

What information were you provided with regarding mental health—increased rates of anxiety and depression?

What information and resources were you provided with about caretaker and family effects?

What resources/services/supports were offered to you or your family throughout your experience with different facilities post-injury?

What did you find helpful that was said to you by professionals after the event? What did you find hurtful or frustrating?

Where did you go to fill in gaps in information when you were confused or needed more information or resources?

What do you know now that would have been helpful to know back then about brain injuries, resources or recovery?

How did you cope and adapt?

What strengths did you develop as a result of the event and this experience?

Appendix C

Katelyn Ryan
2470 Bridgeview CT.
Mendota Heights,
MN 55120

(651) 271-6738

January (?), 2014

Name of Participant
Participant's Address

Dear Participant:

Thank you for contacting me in regards to your interest in participating in my clinical research study! Again, name is Katelyn Ryan and I am a graduate student at St. Catherine University/University of St. Thomas studying Master's of Social Work. I am conducting a study under the guidance of my university chair, Colin Hollidge, PhD, about the self-reported brain injury education information, resource & support needs and experiences of family members/caregivers of brain injury survivors during recovery. You were selected as a possible participant because you have been identified as a caretaker of a family member who is a brain injury survivor. I would like to again, invite you to participate in this research.

Participation in this study would entail being interviewed by myself, in person, regarding your experience with brain injury recovery. I have included a copy of the questions for you to review, a copy of the consent form for you to look over and a list of counseling/crisis resources that will again be provided to you during the interview if you choose to participate. This interview should last forty-five minutes.

This study has been approved by the University of St. Thomas Institutional Review Board and by my committee, which includes my chair, Colin Hollidge, PhD, as well as two other professionals from the community. The research results from this study will provide social workers with a greater understanding of the needs of family members and caregivers, appropriate timing for presentation of educational information and resources, as well as to help identify the current gaps in providing brain injury education and support.

One to two weeks after receiving this letter I will contact you by phone so that we can find a time that works to conduct the interview. In the meantime, if you have any question or concerns feel free to contact me.

Thank you for your time,
Katelyn Ryan

Appendix D

Volunteers Needed for University of St. Thomas Graduate Student's Research Study

Specific Volunteers Needed: Family Members/
Care Takers of individuals who have experienced
a brain injury 1 yr ago or more, who are willing to
take part in a confidential, 45 minute interview
about their experiences post brain injury.

MSW Clinical Research Study Title:
Self-Reported Needs of Family Members/Caregivers of
Traumatic Brain Injury Survivors

The purpose of this study is to gather information on what brain injury
educational information, resources, and support are necessary for
professionals to provide for family members and caregivers of a brain
injury survivor throughout the initial recovery process as well as to
look at the personal experiences of family members and caregivers
surrounding accessibility, helpfulness, and effects of information,
resources, support and interactions with professionals.

If you would like to share your story/experience please call
or email Katelyn Ryan
Ryan6055@stthomas.edu
(651) 271-6738

Identity and all information shared will remain confidential

Appendix E

Resources for Participants

Counseling Services

Crisis Connection: (612) 379-6363

(24 hours a day, 7 days a week over the phone counseling)

C.O.P.E.: (612) 596-1223

(24 hours a day, 7 days a week emotional crisis intervention services)

Walk-In Counseling Center

2421 Chicago Avenue S
Minneapolis, MN 55404
(612) 870-0565 x 100

Hours:

Afternoons

Monday, Wednesday, Friday: 1:00 – 3:00

Evenings

Monday through Thursday: 6:30 – 8:30

Support group for family members, friends & caregivers of brain injury survivors:

Bethesda Hospital

559 N. Capitol Blvd.
St. Paul, MN
(651) 232-2761

Day: 2nd Wednesday of each month

Time: 6-8 pm

Location: B-Level Conference Room

Format: 1st hour education, 2nd hour share and support.

****No prior registration needed—any caregiver/family member/friend can drop in for education & support.**

Minnesota Brain Injury Alliance

The Minnesota Brain Injury Alliance provides resources and information through our Brain Injury Helpline to better connect people affected by brain injury and the professionals who support them with tailored information about available resources and supports.

(612)-378-2742 or 1-800-669-6442

www.braininjurymn.org

Appendix F

Script for Describing Research Project & Participant's Involvement

Script for speaking on the phone when potential participants contact me as well as for the beginning of the interview...

As you read on the flyer, I am a social work graduate student at the University of St. Thomas and I am currently working on my clinical research project. The title of my research project is Self-Reported Needs of Family Members/Caregivers of Traumatic Brain Injury Survivors. For this project I am looking to conduct a 45 minute, audiotaped interview with individuals who are family members/care takers of a brain injury survivor whose injury occurred at least one year ago. The purpose of this study is to gather information on what brain injury educational information, resources, and supports are necessary for professionals to provide for family members and caregivers throughout the initial recovery process. The study also looks at the personal experiences of family members and caregivers surrounding accessibility, helpfulness, and effects of information, resources, support and interactions with professionals. I am hoping that the research results from this study will provide social workers with a greater understanding of the needs of family members and caregivers, appropriate timing for presentation of educational information and resources, as well as to help identify the current gaps in providing brain injury education and support. All information shared as well as identity will be kept completely confidential.

Will then continue with this when using the script for the phone conversation after potential participants have called me...

If you are still interested in learning more about participating in my research study I can send you a copy of the interview questions, the consent form and a list of community support resources for you to look over on your own time. Is this something that you may be interested in? Do you have any questions that I can answer for you now?